Life and Death

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Abstract: In contrast with the other lectures given in the course on humanities and bioethics at the UOEH, which address the questions of life and death from the standpoint of the physician or the philosopher, this lecture considers these issues as seen by the cancer patient who has had a close encounter with death. The attitudes of Americans concerning abortion, the use of life-support systems, "mercy killings", suicide and the use of cancer chemotherapy are discussed with particular emphasis on restraints imposed by the courts, the churches and the family systems. An attempt is made to contrast the American and Japanese attitudes on these questions but this is difficult because of different cultural and religious backgrounds. The author describes his own experiences as a cancer patient who has approached death very closely and the changes in his own attitude toward life which results from the encounter with death. He also talks about the joy of being alive and describes his own experience with receiving cancer chemotherapy, the resulting discomfort and inconveniences and his feelings about a "tolerable" existence. Finally, the author considers the question of the "quality of life" for the cancer patient who has a violent reaction to certain forms of chemotherapy. This is a dilemma for the patient and the doctor who must consider the choice between death and a miserable existence.

Key words: life and death, abortion, life-support, quality of life, cancer chemotherapy.

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Before I begin let me say how happy I am to have the chance to address this class on the issues of life and death. I will be speaking to you not as an authority on ethical behavior in the medical setting but as an individual health scientist who studies life and death issues in the occupational environment and as an individual who has had a rather unique life and death experience which you may find of interest. I am sure that the emphasis in what I will present will be quite different from what your other professors of medicine might tell you. Many of them have had to face these issues in the same fashion as you will. And I am sure that I am not qualified to speak as a philosopher knowledgeable about the ethical decisions of life and death. At the same time I would hope that what I have to tell you today will help you in the future when you are faced with making both medical and ethical decisions about life and death issues.

Until quite recently I had not thought very deeply about these issues. Of course, as an epidemiologist studying the etiology of occupational cancer I had spent much of my time looking at those who survived from and those who died from the hazards of the workplace environment. But in doing this I had no direct contact with the workers who
suffered and died from the occupational diseases. What I was looking at were pieces of paper-employer records, hospital reports and death certificates. I have found in my own personal experience how quickly our attitudes change when we leave the world of cold statistics and are suddenly faced with the reality of death.

Today I will try to tell you about the attitudes of some Americans, both professional and non-professional, regarding several questions of life and death as I interpret them. These will include abortion, the use of life-support systems and the use of chemotherapy for treatment of cancer. And then I also will tell you something of my own experience. As in your country, there has been much concern about these life and death issues, especially as regards who should make the final decisions. While some people might think that these are questions which should be resolved solely between the patient and doctor, there are many in the United States who feel that these issues should be decided, at least in part, in the context of the legal system, the religious system and even the family system.

**Abortion**

First, in the case of abortion, this has become a moral and legal issue which has led to much argument in the United States. Large numbers of people have organized to form PRO-LIFE (Anti-abortion) and PRO-CHOICE (Pro-abortion) groups who work for changes in the law which would favor their approach. Because each of the fifty states in the United States has its own laws regarding abortion, there has been much confusion about the legality or illegality of such procedures. In general, it can be said that most states have permitted abortions until the twenty-eighth week of pregnancy. And appeals to the Supreme Court, which makes the final decision on a national level, have resulted in agreement with this position. At the present time, the PRO-LIFE groups, including many members of the Congress and even the President of the United States, are advocating laws that would declare all abortion illegal and leave the legal interpretation to the courts of the individual states. It should be noted that some of these proposed laws would allow exceptions such as pregnancies resulting from incest or rape.

To understand the reasoning behind the legal arguments which have developed over abortion, you have to understand the role of the Christian churches in American society and the religious beliefs of persons belonging to certain of these churches. Because of the quite different religious backgrounds of our two countries, I am not sure that I can make clear the moral position of various groups of Americans in a way that you would understand. The best I can do is state my own impressions of those positions. There are, at the one extreme, some groups of Americans, both non-church members and church members who believe that the question of abortion should be decided by the pregnant woman and her physician without any interference from others. Some of this group would, however, agree that abortion is wrong at the point in time when the fetus would be
considered viable or able to sustain life outside the womb.

At the other extreme, are those who declare that abortion at any time is murder and who state, as a matter of their religious belief, that life begins at the moment of conception. In the United States there are many shades of opinion between these two points. It is my impression that most Americans take a middle ground between these two views. They are, on the one hand concerned because of their religious background about the taking of a "life". But they are not sure in their own minds as to the correct definition of when life begins. Many of them also express concern about the immorality of bringing unwanted children into the world— an issue which they would try to balance with the potential wrong of destroying the fetus. Finally, on the question of abortion, a unique issue which has been raised in the United States concerns the legal responsibility of the physician to inform the parents when a minor child requests an abortion. In most states a child is treated as a minor until at least age 18 and in some states until age 21.

**Life-Support Systems**

As a second topic, I should like to say a few words about the controversy regarding the use of life-support machines to maintain life. There are again legal and moral questions which have been raised about the decision to use such equipment and the decision to disconnect the equipment. For some years there have been considerable arguments about the need for rules which would specify when such machines should be turned off and the need for a legal definition of death, particularly in the case of removing organs for transplanting to other patients. I understand that most courts in the United States now recognize the lack of any brain function as death for this purpose. I am sure these decisions will be the hardest for you as physicians. You are dedicated to saving and preserving life—and with these machines you are maintaining one life, while you concern yourself with saving the life of the patient who requires the transplant but only after the first life is finished. This is certainly not a simple medical decision but one that requires an ethical decision based on attitudes toward life and death.

As with abortions, the American religious groups have expressed their opinions on these issues and my impression is that most of them feel that it is morally correct to disconnect life-support systems when there is no reasonable hope of saving the life of the patient. However, even when the legal and moral standards of the American society have been met, the doctor is not always certain as to when removal of life-support systems might be justified in the eyes of the patient's family. For that reason it has become common for the doctors to first get the permission of the patient, or more often the family because the patient is comatose, to disconnect the machines. And it is interesting to note that we have had several recent cases where a patient has had to demand through a court procedure that the machines be disconnected when the family insisted
otherwise. It is also interesting to note that many Americans now have “living wills” that instruct the doctor not to take extraordinary means to continue their lives if it is unreasonable to expect recovery. In other words these people do not want to live if life can only be sustained by machines.

A related topic which I will mention briefly is that of “mercy killing”, that is taking the life of a person who has an incurable and often very painful condition. I would say in general that most Americans are strongly opposed to mercy killings but they are also concerned that there is no ethical way to deal with the treatment of such cases. Every week there are newspaper stories about a person who has killed their spouse because they could not continue to watch them suffering. And in a very much publicized case an American physician was recently charged with attempted murder when he refused to give food to his new-born siamese twin children who could not be surgically separated.

Another related issue concerns our attitude toward suicide. There are many people in both of our countries who would argue that the individual should have the right to control his own life and his own death. But others would argue that people who wish to take their own lives are frequently mentally deranged and it is the responsibility of society to protect these people from themselves. I have recently noted a number of newspaper stories about the large number of suicides in the forest near Mount Fuji and it is my impression that suicide is more acceptable in Japan than in the United States.

As a final topic, I should like to say something about the use of chemotherapy in the treatment of cancer and tell you something of my own experience. On September 8, 1981, I was admitted to a hospital in a very anemic condition. I apparently had been losing blood for some time due to a condition which was shortly found to be a malignant tumor of the ascending colon. Looking back now to that time is almost like remembering a dream. It was a very strange experience which has completely changed my outlook on life. The strangest part of the experience was that I thought I was going to die (and I think I came very close). But I was not afraid of death. Now that was very strange to me because if somebody had asked me the day before I entered the hospital about my attitude toward death, I would have told them that the idea was very frightening. But I was not at all afraid. I was very much at peace with myself. I told myself that I had had a fairly long and interesting life which I enjoyed very much and that I should be satisfied with that. This is a feeling which is very hard to explain. Many people in the Western world might attribute my feeling at that time to a religious experience. That is, an attitude of “going to meet my God in another world” which is consistent with my religious background, except that most Christians when faced with death react with fear rather than the peaceful feeling that I had. Because of our different religious and cultural backgrounds, I would be very curious to know how the average Japanese patient would respond to such a situation and if some of them have had the same feeling.

In any case, while I was content to die at that time, I am most happy to be alive
today and to be here telling you about my experience. For that I must give credit to a very skilled surgeon who removed the tumor (along with two adjacent lymph nodes that proved to be cancerous) and to the physicians who have been caring for me since that time. I am sure that you have heard many people say that those who have approached death very closely and recovered seem to have a very different attitude toward life than they did before their illness. As one who has experienced it, I have to agree. But it is not easy to explain. All I can say is that life is so much more enjoyable, in spite of some minor problems of living. And now every little detail of life, no matter how small, is something to be enjoyed. You might be interested to know that one of the nicest things about being alive today is that I was able to come to Japan and have my first experience with eating sashimi and sushi. I would not have had that chance if I had died. Dr. Tsuchiya tells me that by the time I return to the United States I will be a regular fish eater. But he hasn’t given me any suggestions as to where I might find fresh fish in Washington, D.C.

Now for some comments on the chemotherapy. Because of the lymph node involvement and a sharp increase in my CEA level, which suggested the possibility of malignant activity, my doctors decided to put me on a course of chemotherapy which might stem the growth of malignant cells. From what I had heard about the terrible reactions of patients on chemotherapy, this prospect was much more frightening than the idea of death had ever been. In any case, in November 1981 my doctors began weekly administration of 5-FU, initially with 500 milligrams and gradually increasing to 1000 milligrams. Since then the dosage has been decreased somewhat because of certain side effects and I continue to receive 700 milligrams weekly.

Many people who have heard about some of the more violent reactions to chemotherapy ask me whether life is worth living under these circumstances. And my answer is an unqualified yes. This is because I consider my reaction to the drug tolerable to live with. And my doctors tell me that most other patients on this regimen tolerate it rather well. Perhaps I should define “tolerable” in my own case. One day a week, when I receive my chemotherapy, I experience a period of three or four hours of feeling rather badly, although not violently ill. The only way I can describe the feeling is that it is like the feeling you might have the morning after a night of very heavy drinking. The other six days of the week are not too different from what life was like before the chemotherapy. There are some limitations that I didn’t have before. For example, I must limit my intake of alcohol since my level of tolerance apparently has changed. And I now must take insulin every morning to control my diabetes where I had been able to control this condition with a limited diet for the past eight years. When you really enjoy all the other things in life so much, these are inconveniences which can be tolerated.

Unfortunately, what I have just told you about my experience with chemotherapy is not the situation with some other patients on certain other chemotherapeutic programs. I have personally known a number of patients who become violently ill after
receiving therapy and who remain ill for several days after their treatment. This has been a very frightening experience for those patients and some of them have argued that the “Quality of Life” under these conditions is so miserable that they would be better off dead. In fact, I know of several patients who have gone through an apparently successful course of chemotherapy who have refused further treatment when a new malignancy appeared several years later. They chose death over a life which to them was unbearable.

When the patient decides to discontinue chemotherapy, the treating physician has a medical and an ethical dilemma. If treatment is discontinued, the patient will die, and this is inconsistent with the physicians responsibility to maintain life. On the other hand the physician as well as the patient, has to ask what is the quality of the life I am preserving? What kind of a life is this? I have no easy answers to offer you as to the approach which might be considered most appropriate from an ethical standpoint. In fact, perhaps the greatest dilemma for the treating physician is that each case is very different from each other, so than no general rule would apply.

Enjoying life as much as I do, I can only feel great compassion for those who suffer from their treatments and offer them hope by reminding them that many patients who have survived the chemotherapy have also survived the cancer and now like me have a happier life.

I hope I have been able to give you some ideas today that will be of help to you in the future when you have to make the medical and the ethical decisions about treating patients.

生と死

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要旨：本学の医学概論の講義が多く講席者あるいは退席者の立場からなされているのに対し、本講義は死に直面した癌患者の立場から生と死の問題を論じた。まず、治療、生命維持装置の使用、安楽死、自殺、抗癌剤の使用等の問題に対する米国内の態度を、特に法廷、教会、家族はの制約に重点をおいて論じた。これらの問題についての知見と国民の態度の比較も試みたが、文化的、宗教的背景があるにもかかわらず異なるため、比較は困難であった。次いで、筆者自身が癌患者として死に直面した体験から生じた人生観の変化について語った。生きていくことに今までない歓喜を覚える一方で、抗癌剤の副作用による不快と不都合をも体験した結果、人生とは“耐えうるもの”だという境地に到達した。結局のところ、癌の化学療法の激しい副作用に耐える癌患者にとって、人生の“質”が問題だと考えられる。このことは、死か、悲惨な生存かの二択一を迫られる患者・医師の双方にとって考えねばならぬ問題である。（本稿は、昭和57年10月17日、本学5年生に対して行われた医学概論の講義内容）